

# Workshop on Data Sharing Between International Consortia, Brocher Fondation, Geneva, Switzerland 3<sup>rd</sup> -5<sup>th</sup> June 2014

## Workshop Aims

The aim of this workshop is to explore some of the challenges that face the current governance frameworks of international research consortia when global data sharing, such as between consortia is attempted. It will bring together experts who have been working in this field to prepare a publication to identify key issues and initiate a debate about this issue. This workshop will result in:

- 1) Articulate the limitations of current governance structures
- 2) To describe the meta-governance structures that should be developed to enable global sharing between consortia
- 3) To identify how we can accelerate our solutions into policy making
- 4) To write a paper based on our discussions

This workshop will be organised to optimise the benefit of having so many experts in the room and so will consist of formal information sharing sessions as well as less structured breakout groups and writing sessions. The aim is that much of the thinking will be done for this paper at Brocher to maximise the deep conversations permissible because of the face to face opportunity.

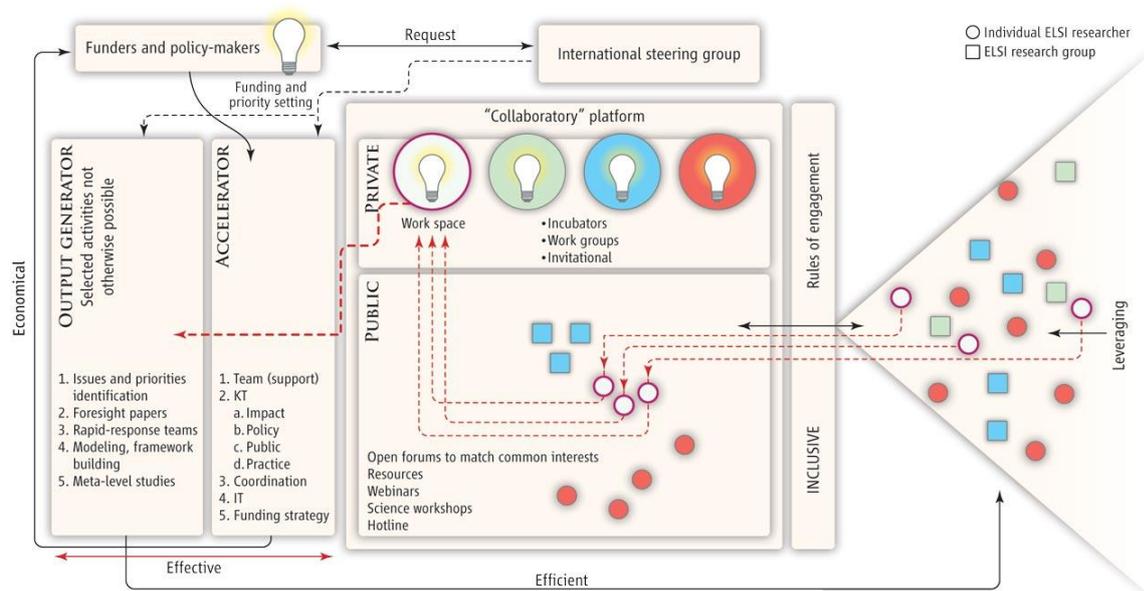
## Background

Increasingly, large international consortia are established to focus on specific research questions and internal governance mechanisms are designed to track and monitor the flow of data and samples. These governance structures have been developed for individual projects. There are questions that are beyond the focus of individual consortia – such as what happens when funding for a consortium ends? Is it sustainable for each project to have its own governance structure? Are these structures different in developing countries where there may be different concerns? How do we involve patients/citizens in consortia governance? Should we be considering a meta-level, global governance framework for consortia? What are the possibilities to use information technology as a form of governance rather than expert committees?

The aim of this meeting is to be a ‘proof of principle’ for the ELSI 2.0 Collaboratory. Currently, ELSI 2.0 facilitates a wide range of activities and hopes to develop more over the coming years, including networking, rapid response, “crowd-sourcing,” modelling, forecasting, and the development of proactive strategies to coordinate and enable international ELSI research. Launched as a “concept” in *Science* (11 May 2012: Vol. 336 no. 6082 pp. 673-674), after being conceived at a meeting of experts at the Fondation Brocher, the ELSI 2.0 Collaboratory aims to anticipate and address the ethical, legal, and social implications of international genomic research. Designed to unify efforts and to catalyze international collaborations, its vision implies a strong commitment to the shared values of respect, trust and collaboration. Overcoming current barriers to international, interdisciplinary research through the development of new, dynamic methods and frameworks will allow researchers to form a global web through which they can interact, while still being able to carry out their work locally. It is expected that this form of collaboration will make global ELSI research more effective, efficient, and economical, thus leading to the development of better local, regional, and international practice and policy.

Having established the need to develop common infrastructures and research platforms, to elaborate on open-access and sharing policies, and to devise new forms of international

collaboration based on the discussions and the publication of the paper in *Science*, the Collaboratory concept now needs to be translated into a living infrastructure. To that end, the purpose of our proposed workshop is to test the Accelerator concept that was outlined in the *Science* paper.



## Detailed list of participants

Jane Kaye, **University of Oxford, UK**  
 Donald Chalmers, **University of Tasmania/ICGC, Australia**  
 Jean McEwen, **National Institutes of Health, USA**  
 Patricia Marshall, **Case Western Reserve University, USA**  
 Eric Juengst, **University of North Carolina, USA**  
 Kazuto Kato, **Osaka University/ICGC, Japan**  
 Clement Adebamowo, **Institute of Virology, Nigeria**  
 Anne Cambon-Thomsen, **INSERM/ICGC, France**  
 Jennifer Harris, **Norwegian Institute of Public Health**  
 Isabelle Budin-Ljøsne, **Norwegian Institute of Public Health**  
 Alistair Kent, **Genetic Alliance UK**  
 Sharon Terry, **Genetic Alliance, USA**  
 Harriet Teare, **University of Oxford, UK**  
 Michael Morrison, **University of Oxford, UK**  
 Madeline Murtagh, **University of Bristol, UK**  
 Rosario Isasi, **McGill University, Canada**  
 Emilomo Ogbe, **University of Ghent, Belgium**  
 Deborah Mascalzon, **University of Uppsala, Sweden**  
 Joel Minon, **University of Bristol, UK**  
 Jusaku Minari, **Osaka University/ICGC, Japan**  
 Edward Dove, **McGill University, Canada**  
 Emmanuelle Rial-Sebbag, **INSERM, France**  
 Sarah Coy, **University of Oxford, UK**